

Talking Point chat room 28 August 2014
Q&A chat on Washing, dressing and incontinence, with Sian from Alzheimer's
Society's National Dementia Helpline

KatherineW	Hi and welcome to the Talking Point chat room. :)
KatherineW	Today's chat is a Q&A session with Sian from our National Dementia Helpline, on the topics of washing, dressing and incontinence. Welcome Sian, and many thanks for visiting the chat room today!
CollegeGirl	Hello, I managed to make it at least for a while - has it started yet?!
KatherineW	Hi CollegeGirl and welcome - we'll be kicking off in a moment, so if you have a question for Sian, please feel free to post it. :)
SianA	Hi there, thank you for having me again. I'm really glad to be here.
CollegeGirl	Hello Sian and welcome - please could you give me some tips to help my dad get my mam washed and dressed every day? She needs help/supervision with this but is almost always uncooperative. Any tips?
SianA	Hi CollegeGirl, thanks for your question. There are a few things that can help. Like...
SianA	It might help to think about whether there are any reasons why they don't want to bathe and if there's anything you can do to fix that. Are they feeling nervous about getting in and out of the bath, or about the depth of the water? You could try keeping it shallow or using a bath chair. Grab rails and a non-slip mat may help.
SianA	With the dressing, you might think about the types of clothes they have and how they can help them be independent; are they easy to get on and off? Buttons, laces and small zips can be fiddly, whereas elastic, Velcro and large poppers can be easier to manage.
SianA	Rather than asking or telling them to change and risking them saying no, you could try offering them a choice between a couple of different options, so that they have some control and are given positive options. They may be able to cope with more limited choices more easily than open ended questions which can feel overwhelming.
SianA	It's tempting to take over but encouraging independence can be more effective, depending on how much they can do. :)
CollegeGirl	Sorry Sian, I wasn't clear enough. I'm talking about just a strip wash at the basin each morning. Carers manage to successfully shower mam on an evening twice a week, and dad tries to get her washed at the basin every morning. She is often violently opposed to this. I have just bought some body wipes to try.
SianA	Body wipes can be effective if someone's very reluctant to get into the bath. Also you could try a bowl of warm water with a soft cloth. Could she use them herself if you guided her hands? It might help her feel more in control.
SianA	Sometimes a really gentle tone can be calming. It can also help if someone's feeling self-conscious to only uncover the part of the body being washed, and then move on to the next area so they don't feel exposed.
CollegeGirl	I think she can do it herself with lots of prompting, encouragement and praise. It's just getting her to agree in the first place that's the problem. I'll suggest the bowl of water, thank you.

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Beate	Can you tell me why it's such a struggle to get appropriate help from the Continence Service? They do not seem to take the fact into account that some dementia sufferers can't cope with some of the methods like catheter etc. They also seem to be understaffed and underfunded - I can only get 2 pull-up pants a day for my OH as they are so expensive apparently.
SianA	Hi Beate, I think it is like you say - understaffed and underfunded. It can be a struggle and it may need a reasoned, possibly written argument about why two pairs of pull ups are not sufficient -that they are damaging to his skin, etc, is he getting a rash at all?
Beate	Yes he gets rashes which we get under control with creams but of course I am not just giving him 2 a day, I give him what he needs and will have to buy more pads when they run out. I just think it should be needs-based not money-based what they decide to give him!
SianA	Hi Beate, Yes, definitely should be needs based, and if they're having to treat problems that are caused by the insufficient pads, that may be grounds for a formal complaint.
SianA	Hi CollegeGirl, does she feel more like washing if she's going somewhere or having visitors? Sometimes motivation can be a stumbling block.
CollegeGirl	Sian, unfortunately not. She has no awareness of 'looking forward' to an event, sadly.
SianA	Hi CollegeGirl, I'm sorry to hear that. If she's really angry and opposed to washing it may be worth trying again at a different time of day - has that ever worked for you? Sometimes it may be that you just need to focus on the minimum for health, like making sure her hands are clean if she's handling food, etc.
Lindy50	My mum lives alone, so it's hard to know what she actually does. But I do know that she wears the same clothes for weeks now. I just watched the podcast (very helpful, thanks) and had a light bulb moment as a result!! Maybe she's sleeping in her clothes, and that's why she thinks she's washed? My problem is in getting mum to agree that there is any problem at all :(
SianA	Hi Lindy50, It's so hard being a carer from a distance, isn't it? You feel the responsibility but don't have the ability to be there to do things for her. It's difficult if you can't check but does she respond to prompts by phone?
Lindy50	Hi Sian :) Whenever I phone, she has always 'just done' everything, or is having a rest 'and will do it later'
Lindy50	Mum is in total denial of any problem with personal care. However, she has agreed that her electric bath chair, which we bought some years ago, no longer works (I think it just needs charging). I've used this as a reason to request an OT assessment, as mum can't get in and out of the bath and doesn't have a shower. She's very unsteady on her feet and it can only be a matter of time before she falls if she does attempt to strip wash.
SianA	Hi Lindy50. Well done on arranging the OT assessment, there may be some help there. You could also look at the Disabled Living Foundation's Living Made Easy website - they have lots of washing aids, and some of them you can try out on a loan

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	basis: http://www.dlf.org.uk/living-made-easy
Lindy50	Ooh, thanks for that link, Sian, I'll give it a good look. I find it really difficult to think through what mum can't do because of arthritis, and what is a result of her dementia.....so all info is gratefully received :)
SianA	Hi Lindy50 - if she has arthritis there are some handy gadgets for getting shoes on without bending over (if you think you can get the hang of it), and elastic laces can be a good option.
Lindy50	Got to go now. Many thanks for your help, Sian
SianA	Hi Lindy50, You're welcome, I hope it turns out to be useful. Take care. :)
SianA	Beate, you also mentioned catheters. Is that something you've experienced with your OH? They can be really difficult for people with dementia and there's not always an easy answer, but the doctors should be taking his confusion into account when planning what treatments are appropriate for him.
Beate	No, I have no experience with catheters but they were suggested to us as a method to use for night-wetting, along with sheets and a few other things, all of which I know he wouldn't be able to cope with
Beate	Continence Service is nurses only really, no doctors.
CollegeGirl	Hi Sian - dad attempts to get her washed and dressed once the first dose of Lorazepam has had chance to kick in. But even then, it often takes him until teatime before she's ready. Washing isn't the only problem. If she refuses to get dressed then they are stuck in the house for the day, and getting out of the house every day is one of dad's coping mechanisms, so it's very difficult. I don't live with them.
SianA	Hi CollegeGirl, That sounds like it's really difficult for your dad, feeling very isolated and bored. Is it possible to get her into any clothing, even if it's inappropriate? If it's warm/cool enough even if she's not super-smart, maybe they could still go out?
SianA	Hi Beate, If you're not happy with the advice you're getting from the continence nurses, you could ask for a referral to a specialist to talk about the pros and cons. Possibly the Bladder and Bowel Foundation could advise too: http://www.bladderandbowelfoundation.org/default.asp
Beate	Thanks - would that referral be via our GP or via the continence service?
SianA	Hi Beate, I think generally the GP would be the first step, unless the continence service has a clinic with a specialist you can book in to see.
CollegeGirl	Hi Sian - it's the agreeing to get dressed that's the problem, rather than the type of clothing ... sorry! I feel so negative.
SianA	Hi CollegeGirl, That is really demoralising when you feel you can't get anywhere with the problem. Does your mam enjoy going out?
CollegeGirl	Hi Sian - well, I don't know if enjoy is the right word exactly! She goes wherever dad takes her - she does like an ice cream for example, and a stroll by a stream. But she

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	still often slaps and kicks dad while they're out, and sometimes refuses to walk with him. She loves children so if there are children around her behaviour is usually better, and that's about as good as it gets I'm afraid.
Beate	Going out when incontinence is involved is tricky - going on holiday is even trickier!
SianA	Hi Beate, Yes, that's something that comes up fairly often on the helpline. If your OH can use toilets, have you heard of the RADAR key system? for locked disabled toilets. Also the Just Can't Wait card can get you into the staff toilets in shops and restaurants, etc. Otherwise, I guess you're generally carrying spare pull ups and a change of clothes?
Beate	yes, but staying over somewhere is near enough impossible as he night wets. Can't really carry mattress covers and Kylie sheets around plus where would I wash them?
SianA	CollegeGirl, I'm just wondering if you and your Dad have much opportunity for a break? It sounds like he only gets to go out if she does too at the moment, and the washing and dressing is becoming a major barrier to that.
CollegeGirl	Hi Sian - in answer to your last question, mam goes for a day at a nursing home twice a week, so yes, dad does get a decent break then. He has just started to have a carer come on those mornings, ostensibly to get mam dressed, but what's actually happening is that her aggression is then focussed on the carer, and she allows dad to get her washed and dressed himself, almost as a bribe for the carer to leave. At least the objective is being met, even if it's the wrong way round!
SianA	Hi CollegeGirl, sometimes it is whatever works, even if it's not ideal.
SianA	Hi CollegeGirl, it sounds as though aggressive symptoms are a big issue for your parents, not just with the personal care. Does your dad have any strategies to try to manage them and keep himself safe?
CollegeGirl	Hi Sian - if things are really bad he locks himself in the bathroom with the phone. But recently the verbal aggression and the awkwardness and being uncooperative have got worse and the actual violence has lessened.
SianA	Hi Beate, overnights are a real challenge. It is a bit limiting in terms of destination, but have you heard of DementiaAdventure (http://www.dementiaadventure.co.uk/) and Vitalise (http://www.vitalise.org.uk/)? They provide holidays for people with dementia and their family/carers, so there is help and understanding about things like continence issues.
Beate	yes, Vitalise is about the only holiday we can take now!
SianA	Hi CollegeGirl, I wondered if you'd seen the Alzheimer's Society factsheet on Aggressive behaviour? It has some strategies for coping with aggression - how to try to manage triggers and how to keep yourself safe (physically and emotionally): http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=96
CollegeGirl	Thank you Sian, yes, we've already read that and used some of the tips. Unfortunately things rarely go the way factsheets expect them to. Dad walks away, mam follows him, she's like a limpet. It's very frustrating and sometimes even

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	dangerous like when he's cooking for example.
SianA	Hi CollegeGirl, That's true, people can't fit into a fixed template. It sounds as though your dad is trying everything. Do you know where her anger is coming from? Is it frustration? Anxiety? Depression? Have you talked to the doctor about it at all, because it sounds like it's really impacting on yours and your dad's wellbeing.
CollegeGirl	Hi Sian - yes, consultant and GP are aware of the problems. GP is very good and has tried lots of different things. Consultant less so unfortunately. She wants mam to go into care, dad is fighting that, so there are clashes, and I'm stuck in the middle able to see both sides of the argument.
SianA	Hi CollegeGirl, that's a really difficult position. It sounds like your dad is really committed to supporting her under incredibly difficult circumstances. Is he getting any support for the emotional toll of caring for your mam?
CollegeGirl	Hi Sian - he was offered some relaxation massages but the manipulations affected some problems he has and made him ill! I think he may have been offered counselling at one point but I can't remember now. I don't think he'd take it up. Part of the problem is that he just isn't bothered about himself, he puts mam first every single time, and it's such a strain. I've talked to him until I'm blue in the face and it makes no difference. He is incredible really, his love and loyalty know no bounds.
SianA	Hi Beate, How did you find the Vitalise holiday? Was it a break for you too?
Beate	Er, not really, it was interesting but I needed a holiday afterwards! It's quite full-on with lots of people and activities
SianA	Hi Beate, you might be joking there, but that's not an outrageous suggestion. He gets his holiday and then maybe you get a break to? Do you have other family who can step in for you to have a rest? :)
Beate	All I get is 3 lousy weeks of respite via social services! Has just been approved. Three lousy weeks...
SianA	Hi Beate, 3 weeks is really short. It's so difficult to get a real break. Have you had a carer's assessment - respite is a service for your OH, but his need for service should be influenced by what your carer's assessment says you can cope with and are entitled to have.
Beate	Yes I had a carer's assessment.
Beate	I also think, changing the topic slightly, that sitters/carers should get incontinence training, at least to hopefully prevent some accidents before they happen. I forever come home to my OH having soiled himself while in the care of a sitting service member who doesn't seem to notice!
SianA	Hi Beate, yes, they should be providing the service based on his need. The continence is a very important aspect of his care, as you said, it's causing him a rash and discomfort. If it's an assessed need, it's part of what any care should be addressing. If it's part of the service the sitters are supposed to provide, it may be that you'd need to take it up as a complaint.

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Beate	Wow - how do you get offered relaxation massages?
CollegeGirl	Hi Beate - I can't remember now, but will ask him and PM you if I find out. He could have had one a month for six months if I remember rightly.
SianA	<p>Hi Beate, Some GP surgeries will offer complementary therapies like massage. It could be worth asking if there's anything like that in your area. There is also this volunteer service from British Red Cross..</p> <p>http://www.redcross.org.uk/en/What-we-do/Health-and-social-care/Independent-living/Hand-arm-and-shoulder-massage</p> <p>.. Also, our Complementary and alternative therapies factsheet is more based on treating people with dementia, but there may be some information general enough to be of interest to the carers as well:</p> <p>http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=134</p>
Beate	Thank you. I would kill for some massages!
SianA	Hi CollegeGirl, sometimes it is difficult to get the carer to see the impact on their own health until it reaches a crisis. Do you think that he would want to talk to someone in confidence on the helpline? He wouldn't have to give his name, and he could just talk it all over. It can be an opportunity to get things off his chest and talk with someone without any feelings to protect.
CollegeGirl	Sian, I hadn't thought of that, thank you, I'll mention it to him. Do I find the number on the website?
SianA	Hi CollegeGirl - it's 0300 222 1122 . We're open 9-5 weekdays and 10-4 weekends (Sundays are usually quiet).
KatherineW	Hi everyone, sorry to interrupt the chat but I wanted to let you know we just have a couple of minutes left of today's session...Sian, you've been brilliant! So much useful info here.
SianA	Hi Katherine, Thank you again for hosting and for inviting me. It's been really interesting to hear everyone's experiences. I hope it's been helpful.
Beate	Yes thanks, Sian
CollegeGirl	Thank you for giving us this opportunity Katherine and Sian, it's good to talk.
KatherineW	Thanks so much for your time today Sian. Beate, Lindy and CollegeGirl (as well as the members who've been viewing), I hope you've found the session helpful. I'll get the transcript posted on the main forum, along with links to further info and resources, asap. :)
SianA	Hi CollegeGirl, thanks for all of your questions. I hope you and your dad are able to get some more help to care for your mum, and feel free to call the helpline!
CollegeGirl	Cheerio everyone and many thanks again.

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Thanks for reading the transcript from our chat room session on 28 August. Some helpful resources on this topic are listed on the following pages.

Alzheimer's Society factsheet on Dressing:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=142

Alzheimer's Society factsheet on Washing and bathing:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=155

Alzheimer's Society factsheet on Managing toilet problems and incontinence:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=136

Alzheimer's Society factsheet on Unusual behaviour:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=159

Alzheimer's Society factsheet on Urinary Tract Infection (UTI) and dementia:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1777 (UTIs can cause sudden problems with continence)

Alzheimer's Society factsheet on Coping with memory loss:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=123

Alzheimer's Society factsheet on Staying involved and active:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=115 (contains advice on maintaining everyday skills)

Alzheimer's Society National Dementia Helpline

If you have concerns about Alzheimer's disease or about any other form of dementia, Alzheimer's Society National Dementia Helpline **0300 222 1122** can provide information, support, guidance and signposting to other appropriate organisations.

The Helpline is usually open from **9am to 5pm Monday to Friday** and **Saturday and Sunday 10am - 4pm**.

You can also email the helpline team at helpline@alzheimers.org.uk.

(Resources list continues on next page)

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RADAR – the Disability Rights People

Disability Rights UK

12 City Forum

250 City Road

London EC1V 8AF

T 020 7250 3222

E enquiries@disabilityrightsuk.org

W www.radar-shop.org.uk

The RADAR National Key Scheme offers disabled people independent access to locked public toilets around the country. Toilets fitted with National Key Scheme locks can now be found in shopping centres, pubs, cafés, department stores, bus and train stations and many other locations in most parts of the country.

Bladder and Bowel Foundation

SATRA Innovation Park

Rockingham Road

Kettering NN16 9JH

T 01536 533255 (general enquiries)

0845 345 0165 (helpline)

E info@bladderandbowelfoundation.org

W www.bladderandbowelfoundation.org

A charity for adults affected by bladder and bowel problems. It provides information and support for individuals, patients, carers and healthcare professionals. The Foundation also sells the Just Can't Wait toilet card.

Disabled Living Foundation/Living Made Easy

<http://www.dlf.org.uk/living-made-easy>

0300 999 0004

Advice and information about disability aids, including dementia.

AT Dementia

www.atdementia.org.uk

Sell dementia related gadgets and aids. No phone calls but can shop online

If you have questions about our chat room, please contact us by emailing
talkingpoint@alzheimers.org.uk

You can view the chat room here: <http://forum.alzheimers.org.uk/chatroom.php>